

## Prioritisation of research topics for head and neck cancer in Africa – Report of the International Collaboration On Improving Cancer outcomes in low and middle income countries – IConIC Africa

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# **Prioritisation of research topics for head and neck cancer in Africa – report of the International Collaboration On Improving Cancer outcomes in low and middle income countries – IConIC Africa**

## **Introduction**

Over the past two decades, the burden of cancer in low and middle income countries (LMICs) has increased steadily<sup>1,2</sup>. However many LMICs have limited access to the full array of cancer treatments: 70% of developing countries having no access to radiotherapy at all, and 98% of patients in low income countries have no access to timely, safe affordable surgery<sup>3-5</sup>. As a result, at least 66% of people diagnosed with cancer in LMICs die from their disease, in contrast to less than 50% in high income countries (HICs)<sup>6</sup>. The burden of disease in LMICs is further heightened by constrained access to allied health services and palliative care expertise. In LMICs, where resources are already very stretched, delivery of research, addressing the specific problems these countries encounter, is consequently limited.

The International Collaboration On Improving Cancer outcomes in low and middle income countries - Africa (IConIC Africa) was established to help identify and develop research to address the most pressing research needs in cancer management in Africa. The Collaboration comprises front-line stakeholders in cancer care in Africa, including clinicians, patient advocacy groups, training organisations, higher education institutes, and policy makers across 14 African countries, along with two universities and professional bodies in the UK (Table 1).

Head and neck cancer (HNC) in Africa is the first cancer site to be studied by the collaboration, as it was deemed to be a good model for a cancer that is relatively common in Africa and results in considerable burden to the patient. It affects all population groups, especially those with socioeconomic deprivation, and results in considerable disease burden to the patient and is relatively common in Africa. Detailed data are difficult to obtain, as many countries' population level incidence data is not collected or is over a decade old<sup>7,8</sup>. In South Africa, where the data quality is highest, the total incidence of HNC (when including all its component subsites) makes it the 3<sup>rd</sup> most common cancer in men, and 6<sup>th</sup> most common in women<sup>9</sup>. The majority of HNC in LMICs present with advanced disease<sup>10</sup>, and due to its anatomical site and treatments, HNC poses one of the highest functional deficits of any cancer<sup>11</sup>; it therefore represents a considerable unmet need in Africa.

To improve cancer management outcomes in Africa, it is important to utilise interventions that have been shown to be effective in that setting. To facilitate the generation of this evidence, we undertook this study to identify and prioritise the most important research questions addressing the areas of greatest unmet need relating to head and neck cancer management across Africa.

## **Methods**

We used a previously published research prioritisation process based on a modified Delphi method<sup>12</sup>; utilising an iterative process that allows consensus on areas of greatest unmet need through voting rounds, interspersed with group feedback.

The process comprised of two online voting rounds, each of which was followed by a face to face workshop with key stakeholders (figure 1).

Initially, an online survey was established and data collected and managed using the Research Electronic Data Capture (REDCap) platform hosted at University of Birmingham<sup>13,14</sup>. REDCap is a secure, web-based software platform designed to support data capture for research studies, providing 1) an intuitive interface for validated data capture; 2) audit trails for tracking data manipulation and export procedures; 3) automated export procedures for seamless data downloads to common statistical packages; and 4) procedures for data integration and interoperability with external sources. The survey was composed of free text fields and was completed anonymously. It asked participants to give, in their opinion, the 3 most pressing issues relating to head and neck cancer management that needed research within each of five pre-defined domains: pre-treatment, treatment, post-treatment, end of life care, and clinical and research training. Respondents also gave information on their role, the type of organisation they worked in, and their country of residence. The survey was circulated to the IConIC Africa group representatives asking them to disseminate the survey via peer to peer networking to ensure the greatest number and scope of responders. The survey was open for a period of 4 weeks, from 27<sup>th</sup> October to 24<sup>th</sup> November 2018, after which responses were collated.

All responses were descriptively assessed, categorised into common themes, and analysed. A face to face meeting was held with key stakeholders in Cape Town, South Africa, on 29<sup>th</sup> November to 1<sup>st</sup> December 2018. The stakeholders included clinicians, patients, patient advocacy groups, higher education institutes, hospital managers, social workers, dieticians, and policy makers. The meeting reviewed the responses and themes within each domain determined from the survey, and the 3 most common themes in each domain were then formulated into specific research questions.

The second stage online survey was distributed in the same way as in the first one, and was also open for 4 weeks (1<sup>st</sup> to 29<sup>th</sup> March 2019). In this round participants were asked to order the three priority questions in each of the five domains in order of importance. They were also asked to indicate the top three priorities overall from the list of 15.

Following analysis of the data from the second survey, a further workshop was held on 6<sup>th</sup>-7<sup>th</sup> July 2019, in Cape Town, South Africa, attended by a the same key stakeholders. The results of the second survey were discussed at this face to face workshop to decide on the research topics and to formulate the research studies to be undertaken by the Collaborative. A preliminary stakeholder analysis was also undertaken.

## **Results**

### **Phase 1: Identification of areas of greatest unmet need**

A total of 60 individuals from 12 countries completed the first stage survey, covering a wide range of roles relating to head and neck cancer, and cancer care as a whole (figure 2). These included all types of clinicians involved in cancer care (surgeons, medical and radiation

oncologists, palliative care physicians), allied healthcare professionals, a patient advocacy group, and a policy maker. Most clinician responders worked in urban hospitals with > 200 beds (76%), and with access to critical care facilities (82%).

The main priority areas identified by the respondents are shown below (table 2). These were themed by two members of the steering group independently. The top responses were late presentation of disease, poor compliance with follow up, difficulties with access to investigations and poor community hospice support.

#### Phase 2: Workshop 1

The first workshop reviewed the responses and themes within each domain, and the three most common themes in each domain were phrased as specific research questions, which were then formulated into an online survey. The research questions are shown in table 3.

#### Phase 3: Second round voting

The second survey was then circulated using the same distribution model. It asked respondents to rank each of the 3 research questions within each domain in terms of priority. In addition, a final question asked respondents to rank all 15 questions overall in terms of importance, regardless of domain.

Thirty nine responders from 8 countries completed the survey, again with a wide range of roles relating to head and neck cancer care and patient advocacy. On analysis, the question ranked as first within each domain was assigned 5 points, the second 3 points, and the third 1 point, with a highest attainable score of 195 (if ranked first by each of the 39 responders). The highest ranked priorities are shown in table 4.

For overall ranking, the reasons for late presentation scored the highest (being identified as one of the top three most important questions overall) by 22 of 39 respondents (56.4%). This was followed by improving access to specialist care (17/39, 43.6%), then streamlining pathways of investigation and treatment (14/39, 35.9%).

#### Phase 4: Research planning workshop

A workshop was held on 6<sup>th</sup>-7<sup>th</sup> July 2019, in Cape Town, South Africa, attended by 27 delegates representing 8 African countries. The results of the prioritisation process were presented, and a consensus reached that the initial priority for the Collaborative would be to examine reasons for and develop interventions to address late presentation of patients with head and neck cancer.

### Discussion

Head and neck cancer is an under-represented disease in terms of resource allocation, public awareness and research funding in LMICs. The IConIC Africa group seeks to help address this. As a first step we sought to undertake a research prioritisation process to identify the research areas of greatest need pertaining to head and neck cancer care across Africa. A key aim was to involve patients and patient advocacy groups, policy makers, evidence synthesis experts, and research and training bodies, as well as clinicians, in Africa from the outset, so as to ensure that the outcomes were representative of the setting.

Identifying and understanding the reasons for late presentation was reported as the area of highest priority for those involved in the care of patients with HNC in Africa.

The modified Delphi method has been used to identify research priorities in a number of medical fields<sup>15</sup>, and is one of a number of prioritisation methodologies used internationally<sup>16,17</sup>. We used this process in our study as it allowed for the rapid accumulation of data from a geographically disparate group. Whilst we used it for head and neck cancer in Africa, this process could be used to potentially assess priorities across other countries and regions in the Global South, and for other cancer sites.

Despite wide distribution, many African countries were not represented. This is in part due to the lack of engagement in healthcare research in some countries, often due to the heavy workload of clinicians being such that no time or resources are available to engage in any other activity than direct patient care<sup>18</sup>.

Late presentation is not unique to HNC in LMICs. Research has been undertaken to examine factors that contribute to the late presentation of other malignancies, including breast, cervical and oesophageal cancer<sup>19–22</sup>. However, little work has been done in HNC, which has an additional set of challenges, relating to loss of function and stigma from visible disfigurement, that may also contribute to late presentation.

The priorities ranked second and third overall are also components of the “pre-treatment” domain, and this is again a common theme amongst studies identifying ways in which cancer care can be improved in LMICs. Indeed, improving access to specialist care as well as streamlining pathways of investigation may itself contribute to reducing late presentation amongst patients with HNC.

The next work stream of the IConIC programme will be to identify, through systematic reviews, qualitative research and stakeholder engagement, the factors that contribute to late presentation, and to then develop interventions to address these.

## **Tables**

African Head and Neck Society
African Cancer Institute
African Organisation for Research and Training in Cancer (AORTIC)
African Palliative Care Association
British Association of Head and Neck Oncologists (BAHNO)^
Cancer Alliance*
Cancer Research Initiative
Cancer Heroes*
CANSA*
Chronic Disease Initiative for Africa
Cochrane Africa
Egyptian Society of Head and Neck Oncology
Ghana Health Service
Jembi Health Systems
Kings College London^
South African Medical Research Council
Stellenbosch University
University of Birmingham^
University of Cape Town

Table 1: ICONIC Africa Collaboration (\*patient group, ^ UK group)

<b>Domain</b>	<b>Themed topics</b>
Pre-treatment care and pathways	<ul style="list-style-type: none"> <li>• Patient awareness of symptoms (21)</li> <li>• Clinician awareness of symptoms (10)</li> <li>• Late presentation/lack of early diagnosis (31)</li> <li>• Pre-treatment optimization (11)</li> <li>• Availability of histopathology (5)</li> <li>• Problems with the stigma of cancer (9)</li> <li>• Poor access to care (7)</li> <li>• Pathways not obvious (9)</li> <li>• Access to investigations (26)</li> </ul>
Treatment	<ul style="list-style-type: none"> <li>• Lack of resources (40)</li> <li>• Cost of treatment (20)</li> <li>• Non-compliance with treatment (8)</li> <li>• Psychosocial support to complete treatment (8)</li> <li>• Controversies in histopathology reporting (2)</li> <li>• Speech rehabilitation (7)</li> <li>• Influence of comorbidities (4)</li> <li>• Difficult to follow international guidelines (8)</li> <li>• Recovery and rehabilitation after surgery (3)</li> </ul>

Post-treatment care and follow up	<ul style="list-style-type: none"> <li>• Poor community based support (6)</li> <li>• Difficulty making follow up/poor compliance with follow up (28)</li> <li>• Poor CNS support (9)</li> <li>• Poor support for side effects of treatment (13)</li> <li>• Ongoing rehabilitation (11)</li> <li>• No survivorship program (10)</li> <li>• Difficult to pick up early recurrence (13)</li> </ul>
End of life care	<ul style="list-style-type: none"> <li>• Limited palliative care services available (21)</li> <li>• Lack of awareness of importance of palliative care as part of MDT (4)</li> <li>• Community hospice support lacking (26)</li> <li>• Unable to manage patients at home (14)</li> <li>• Psychosocial/spiritual support availability (12)</li> <li>• Cost of end of life drugs (11)</li> <li>• Cultural differences in attitude to death (7)</li> <li>• Support and training for oncology staff (7)</li> </ul>
Clinical and research training	<ul style="list-style-type: none"> <li>• Limited funds for research/difficult to access research funding (21)</li> <li>• Support with grant writing (6)</li> <li>• Training in research methodology (19)</li> <li>• Funding for collaborators (3)</li> <li>• Clinical staff already over-loaded with work (9)</li> <li>• Clinical guidelines needed along the care pathway (3)</li> <li>• Data quality improvement (2)</li> </ul>

Table 2: Themed responses from the first round survey (number of responses received for each theme in brackets)

<p><i>Pre-treatment care and pathways</i></p> <ul style="list-style-type: none"> <li>• What are the reasons for late presentation amongst head and neck cancer patients, and how can this be improved?</li> <li>• How can pathways of investigation and treatment be improved to streamline care?</li> <li>• How can resources be optimised to improve access to specialist treatment?</li> </ul>
<p><i>Treatment</i></p> <ul style="list-style-type: none"> <li>• What are the barriers to accepting and complying with treatment?</li> <li>• How can the histopathological reporting of specimens be improved, made more timely and made more standardised across all regions?</li> <li>• What low cost interventions could be made to significantly improve outcomes of treatment?</li> </ul>
<p><i>Post-treatment care and follow up</i></p> <ul style="list-style-type: none"> <li>• What are the reasons for poor compliance with follow up and for late detection of recurrence?</li> <li>• How can community support be maximised to facilitate earlier discharge from hospital?</li> <li>• How could effective survivorship programmes reduce the stigma associated with a diagnosis of cancer?</li> </ul>
<p><i>End of life care</i></p>

<ul style="list-style-type: none"> <li>• How can pathways, training and resourcing be improved to allow greater access to palliative care?</li> <li>• What are the best interventions for end of life care in low resource settings?</li> <li>• What are the barriers to people receiving end of life care, and how is it best to address them?</li> </ul>
<p><i>Clinical and research training</i></p> <ul style="list-style-type: none"> <li>• How can a culture of research be fostered and maintained on a local, national, and international level?</li> <li>• What are the barriers to effective research training?</li> <li>• What are the best designs and methodologies for delivering effective clinical research in low cost settings?</li> </ul>

Table 3: Research questions developed following steering group workshop.

<p><i>Pre-treatment care and pathways:</i></p> <p>What are the reasons for late presentation amongst head and neck cancer patients, and how can this be improved? (135)</p>
<p><i>Treatment:</i></p> <p>What low cost interventions could be made to significantly improve outcomes of treatment? (124)</p>
<p><i>Post-treatment care and follow up:</i></p> <p>What are the reasons for poor compliance with follow up and for late detection of recurrence? (163)</p>
<p><i>End of life care:</i></p> <p>What are the best interventions for end of life care in low resource settings? (103)</p>
<p><i>Clinical and research training:</i></p> <p>What are the best designs and methodologies for delivering effective clinical research in low cost settings? (123)</p>

Table 4: Highest ranked priorities (score out of 195 in parentheses)



## **Figures**

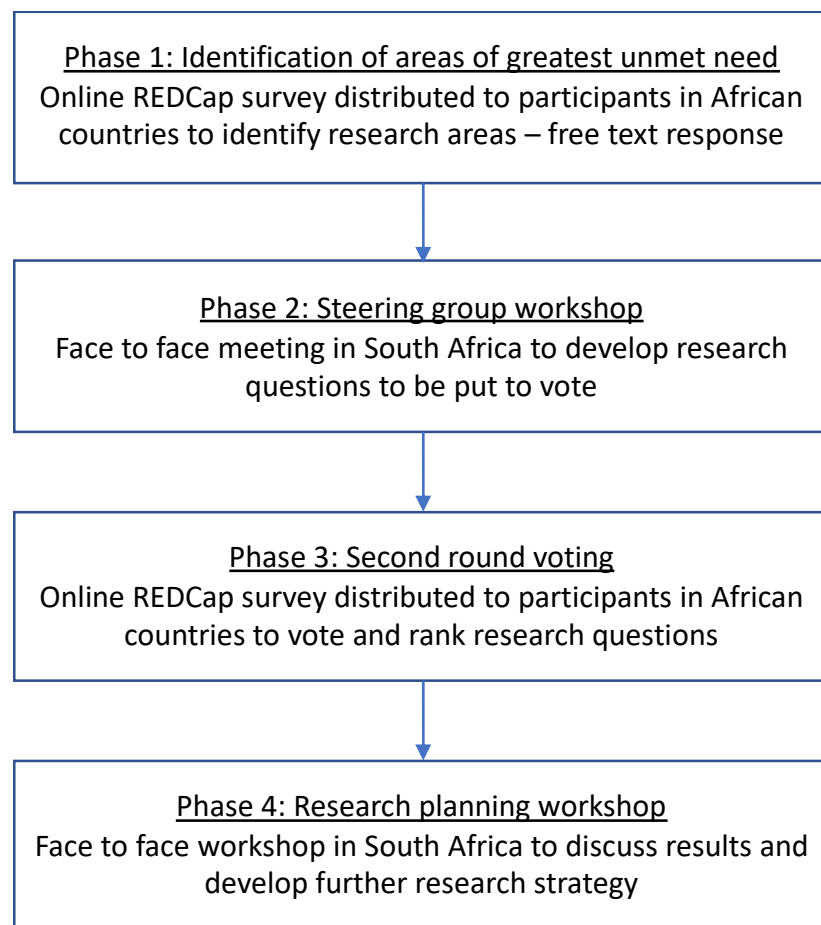


Figure 1: Overview of prioritisation process

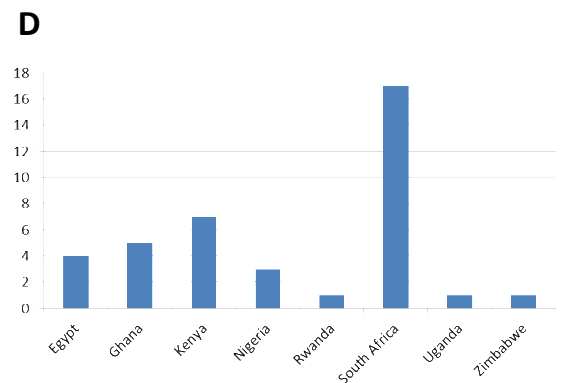
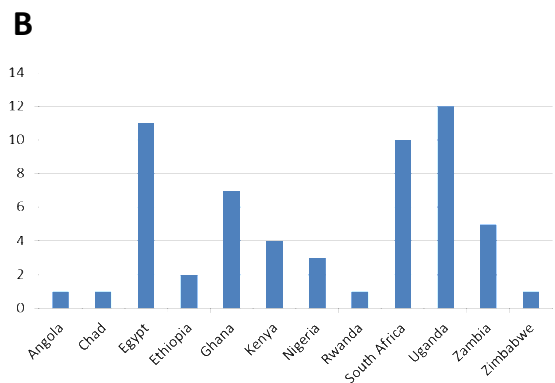
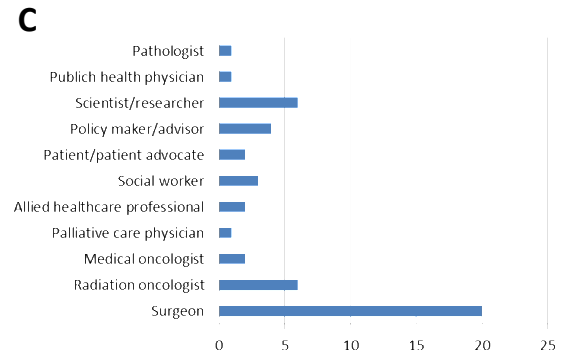
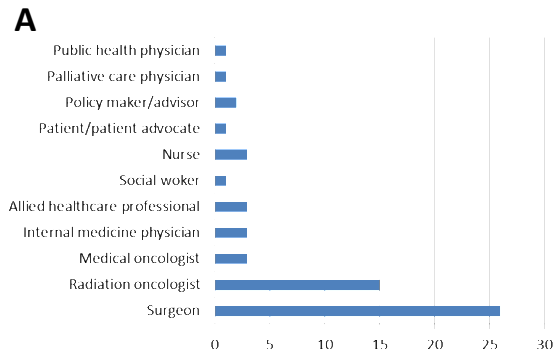


Figure 2: A – Country of residence of respondents and B - Role of respondents in phase 1 survey. C – Country of residence of respondents and D - Role of respondents in phase 2 survey

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